

TITLE 77: PUBLIC HEALTH
CHAPTER I: DEPARTMENT OF PUBLIC HEALTH
SUBCHAPTER f: EMERGENCY SERVICES AND HIGHWAY SAFETY

PART 550
HEAD AND SPINAL CORD INJURY CODE

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550.APPENDIX A	Head and Spinal Cord Injury Reporting/Violent Injury Reporting (Repealed)

AUTHORITY: Implementing the Head and Spinal Cord Injury Act [410 ILCS 515] and authorized by Section 2310-195 of the Civil Administrative Code of Illinois [20 ILCS 2310/2310-195].

SOURCE: Adopted at 15 Ill. Reg. 1068, effective January 15, 1991; amended at 22 Ill. Reg. 5047, effective March 10, 1998; amended at 46 Ill. Reg. _____, effective _____.

Section 550.100 Definitions

The definitions listed in this Section apply to this Part.

"Act" means the Head and Spinal Cord Injury Act [410 ILCS 515].

"Bona Fide Researcher" means an individual with prior experience in conducting published medical or epidemiological studies. This includes but is not limited to prior experience with the publications of medical and/or epidemiological research, or scientific affiliation with a hospital or accredited U.S. university. The researcher must, at minimum, possess a master's degree from an accredited U.S. university in a medical or scientific discipline. Educational degrees in political science, law, or journalism shall not fulfil the educational requirement.

"Council" means the Advisory Council on Spinal Cord and Head Injuries, created within the Department of Rehabilitation Services pursuant to Section 6 of the Act. (Section 1 of the Act)

"Department" means the Department of Public Health. (Section 1 of the Act)

"Head Injury" means a sudden insult or damage to the brain or its coverings, not

of a degenerative nature, which produces an altered state of consciousness or temporarily or permanently impairs mental, cognitive, behavioral or physical functioning. Cerebral vascular accidents, aneurysms and congenital deficits are excluded from this definition. (Section 1 of the Act)

"Hospital" has the meaning ascribed to that term in the Hospital Licensing Act [210 ILCS 85].

"Spinal Cord Injury" means an injury that occurs as a result of trauma, which involves spinal vertebral fracture, or where the injured person suffers any of the following effects: effects on the sensory system including numbness, tingling or loss of sensation in the body or in one or more extremities; effects on the motor system including weakness or paralysis in one or more extremities; effects on the visceral system including bowel or bladder dysfunction or hypotension. (Section 1 of the Act)

(Source: Amended at 46 Ill. Reg. _____, effective _____)

Section 550.110 Incorporated and Referenced Materials

a) The following standards are incorporated in this Part:

World Health Organization International Classification of Diseases, which may be accessed at <https://www.who.int/standards/classifications/classification-of-diseases>

- ~~1) Glasgow Coma Scale
Champion HR, Sacco WJ, Camazzo AJ et al.:
CritCare Med 9(9):672-676 (1981)~~
- ~~2) International Classification of Diseases, 9th Revision,
Clinical Modification (ICD-9-CM)
Alphabetic Index to External Causes of Injury (E-Codes)
Second Printing (1980)
World Health Organization, Geneva Switzerland and
National Center for Health Statistics
Published by Edward Brothers, Inc.
1968 Green Road
Ann Arbor, Michigan 48105~~

~~b) All incorporations by reference of the standards of nationally recognized organizations refer to the standard on the date specified and do not include any additions or deletions subsequent to the date specified.~~

be) The following statutes are referenced in this Part:

- 1) Hospital Licensing Act [210 ILCS 85];
- 2) Head and Spinal Cord Injury Act [410 ILCS 515].

(Source: Amended at 46 Ill. Reg. _____, effective _____)

Section 550.120 Reporting Requirements

- a) *The Department shall establish and maintain an information registry and reporting system for the purpose of data collection and needs assessment of head and spinal cord injured persons in this State. (Section 2 of the Act)*
- b) Each hospital with an emergency department must report electronically the required information as specified by the Division of Emergency Medical Service.~~in subsection (c) of this Section using either: The Department shall provide access to internet-based data collection software for submission of required information.~~
 - 1) ~~a computerized software supplied by the Department. The facility must supply a 486 microprocessor, 32 megabytes of Random Access Memory (RAM), adequate hard drive disk space to accommodate the hospital's data files and needs, at least a 14.4 kilobytes per second (kbs) modem, color monitor, printer and back-up capabilities; or~~
 - 2) ~~a paper form for each reportable case. The master format will be provided by the Department and will be reproduced by the reporting facility. (See Appendix A.)~~
- c) All hospitals with emergency departments shall report~~provide the following~~ information quarterly on each patient diagnosed as a head or spinal cord injured patient who is ~~admitted to the hospital or arrives at the emergency department and dies before admission to the hospital:~~
 - 1) Admitted to the hospital as an in-patient admission, including observation admissions; patients that are admitted to the emergency department and die before in-patient admission; or Patient Name;
 - 2) Transferred to another acute care hospital for definitive treatment of the head or spinal cord injury. Hospital Name;

130	3)	Hospital Code Number;
131		
132	4)	Pre-Hospital Number;
133		
134	5)	Crash Number;
135		
136	6)	Medical Record Number;
137		
138	7)	Arrival Date;
139		
140	8)	Birthdate;
141		
142	9)	Age in Years;
143		
144	10)	Sex;
145		
146	11)	Race;
147		
148	12)	Injury Date;
149		
150	13)	Federal Information Processing Standard (FIPS) Scene;
151		
152	14)	Scene City;
153		
154	15)	FIPS Home;
155		
156	16)	Home City;
157		
158	17)	E-Code (External Cause of Injury);
159		
160	18)	E-Code 849 (Place of Injury);
161		
162	19)	Work Related;
163		
164	20)	Safety Equipment;
165		
166	21)	Alcohol;
167		
168	22)	Drugs;
169		
170	23)	Glasgow Score Total (Emergency Department);
171		
172	24)	Systolic Blood Pressure (Emergency Department);

- ~~25) Respiratory Rate (Emergency Department);~~
- ~~26) Respiratory Status (Emergency Department);~~
- ~~27) Disposition (Emergency Department);~~
- ~~28) Nature of Injury Code (ICD-9-CM);~~
- ~~29) Discharge Disposition;~~
- ~~30) Facility Out (facility to which the patient was transferred);~~
- ~~31) Hospital Days;~~
- ~~32) Expression (ability to speak);~~
- ~~33) Feeding (ability to feed self);~~
- ~~34) Locomotion (ability to move about);~~
- ~~35) Rehabilitation Potential;~~
- ~~36) Billed Charges (Hospital charges only); and~~
- ~~37) Primary Payment Source.~~

d) The required information to be reported can be found on the Department's website at: <https://dph.illinois.gov/topics-services/emergency-preparedness-response/ems/trauma-program/headspinal-cord-and-violent-injury-registry-hsvi.html>~~Reportable head and spinal cord injuries include the following ICD-9-CM Codes:~~

- ~~1) 800 Fracture of vault of skull;~~
- ~~2) 801 Fracture of base of skull;~~
- ~~3) 802 Fracture of face bones except nasal bones;~~
- ~~4) 803 Other and unqualified skull fractures;~~
- ~~5) 804 Multiple fractures involving skull or face with other bones;~~

- ~~6) 805 Fracture of vertebral column without mention of spinal cord lesion;~~
- ~~7) 806 Fracture of vertebral column with spinal cord lesion;~~
- ~~8) 839 Other, multiple and ill-defined dislocations;~~
- ~~9) 850 Concussions;~~
- ~~10) 851 Cerebral laceration and contusion;~~
- ~~11) 852 Subarachnoid, subdural and extradural hemorrhage, following injury;~~
- ~~12) 853 Other and unspecified intracranial hemorrhage following injury;~~
- ~~13) 854 Intracranial injury of other and unspecified nature;~~
- ~~14) 925 Crushing injury of face, scalp, and neck;~~
- ~~15) 926 Crushing injury of trunk;~~
- ~~16) 950 Injury to optic nerve and pathways;~~
- ~~17) 951 Injury to other cranial nerves;~~
- ~~18) 952 Spinal cord lesion without evidence of spinal bone injury; and~~
- ~~19) 953 Injury to nerve roots and spinal plexus.~~

e) The reporting schedule is~~Reporting deadlines are~~ as follows:

Patient <u>Admission</u> Discharge	Report Due Date
January – March	June 30
April – June	September 30
July – September	December 31
October – December	March 31

(Source: Amended at 46 Ill. Reg. _____, effective _____)

Section 550.130 Confidentiality and Availability of Data

- a) *All reports and records made pursuant to the Act and maintained by the Department and other appropriate persons, officials and institutions pursuant to the Act shall be confidential. Information shall not be made available to any*

individual or institution except to:

- 1) *Appropriate staff of the Department;*
- 2) *Any person engaged in a bona fide research project, with the permission of the Director of Public Health, except that no information identifying the subjects of the reports or the reporters shall be made available to researchers unless the Department requests and receives consent for such release pursuant to the provisions of this Section; and*
- 3) *The Council, except that no information identifying the subjects of the reports or the reporters shall be made available to the Council unless consent for release is requested and received pursuant to the provisions of this Section. Only information pertaining to head and spinal cord injuries as defined in Section 1 of the Act shall be released to the Council. (Section 3 of the Act)*
- 4) The Department for the purpose of injury prevention or determining the impact of head and spinal cord injuries
 - A) All information and data shared with the Department shall be kept confidential and limited to the scope of the project. No data may be shared with the Department that could lead to the identity of any facility, or the identity of any person whose condition or treatment is submitted to the Department.
 - B) The Department requesting data shall enter into a written agreement with the Division of EMS which shall include, at minimum
 - i) Data being requested,
 - ii) Proposed usage of data,
 - iii) Responsible Individual charged with ensuring the confidentiality of the data
 - C) The written agreement must be approved by each Department Deputy Director and the Director of the Department.
- b) *The Department shall not reveal the identity of a patient, physician or hospital, except that the identity of the patient may be released upon written consent of the patient, parent (in the case of a minor patient) or guardian, the identity of the*

physician may be released upon written consent of the physician; and the identity of the hospital may be released upon written consent of the hospital. (Section 3 of the Act)

c) The Department shall request consent for release from a patient, a physician or hospital only upon a showing by the applicant for such release that obtaining the identities of certain patients, physicians or hospitals is necessary for his bona fide research directly related to the objectives of the Act. (Section 3 of the Act)

d) The Department shall at least annually compile a report of the data accumulated through the reporting system established under Section 2 of the Act and shall submit such data relating to spinal cord and head injuries in accordance with confidentiality restrictions established pursuant to the Act to the Council. (Section 3 of the Act)

e) Head and Spinal Cord Injury Registry data may be provided for medical or epidemiological research by bona fide scientific researchers in accordance with Part (f) of this Section. All requests by bona fide scientific researchers for such data must be submitted in writing to the Department at <https://dph.illinois.gov/data-statistics/institutional-review-board.html>. ~~All requests by medical or epidemiologic researchers for confidential Registry data must be submitted in writing to the Registry.~~ The request must include a study protocol that contains: objectives of the research; rationale for the research including scientific literature justifying the current proposal; overall study methods, including copies of forms, questionnaires, and consent forms used to contact facilities, physicians or study subjects; methods for the processing of data; storage and security measures taken to ensure confidentiality of patient and facility identifying information; time frame of the study; a description of the funding source of the study (e.g., federal contract); the curriculum vitae of the principal ~~researcher~~ investigator and a list of collaborators. In addition, the research request must specify what patient or facility identifying information is needed and how the information will be used.

f) All requests to conduct research and modifications to approved research proposals involving the use of data that includes patient or facility identifying information shall be subject to a review to determine compliance with all the following conditions:

- 1) The request for patient or facility identifying information contains stated goals or objectives.
- 2) The request documents the feasibility of the study design in achieving the stated goals and objectives.

- 3) The request documents the need for the requested data to achieve the stated goals and objectives.
 - 4) The requested data can be provided within the time frame set forth in the request.
 - 5) The request clearly documents that the principal researcher has qualifications relevant to the type of research being conducted and qualifies as a bona fide researcher.
 - 6) The research will not duplicate other research already underway using the same registry data when both require the contact of a patient, reporting facility or physician about an individual patient involved in the previously approved concurrent research.
 - 7) Other such conditions relevant to the need for the patient or facility identifying information and the patient's confidentiality rights. ~~The~~because ~~the~~ Department will only release the patient, physician in accordance with the provisions of this Section, or facility identifying information that is necessary for the research.
- g) The Department will enter into a written Research Agreement for all approved research requests. The Agreement shall specify the information that is being released and how it can be used, in accordance with subsection (ee) above. The Department will only provide available data relevant to the goals and objectives of the specific research approved by the Department.
- h) The identity of any facility or individual, or any group of facts that tends to lead to the identity of any person whose condition or treatment is submitted to the Department, shall not be open to public inspection or dissemination. Such information shall not be available for disclosure, inspection or copying under the Freedom of Information Act or the State Records Act. Only information for specific research purposes may be released in accordance with procedures established by the Department in this Section.
- i) Every hospital shall provide representatives of the Department with access to information from all medical, pathological, and other pertinent records and logs related to reportable registry information. The Department shall not require hospitals to provide information on cases that are dated more than two years before the Department's request for further information.
- j) Every hospital shall provide access to information regarding specified patients or

other patients specified for research studies, related to reportable registry
information, conducted by the Department.

(Source: Amended at 46 Ill. Reg. _____, effective _____)

Section 550.APPENDIX A Head and Spinal Cord Injury Reporting/Violent Injury Reporting (Repealed)

~~PART 1~~

Hospital Name _____		code _____
Prehospital Number	NA	Unk ___/___/___
Crash Number	NA	Unk ___/___/___/___/___/___/___
Med. Record Number	NA	Unk ___/___/___/___/___/___/___/___/___
Patient Name		last first initial
ED Arrival Date		___/___/___ (mo/dd/yy)
Birthdate	Unk	___/___/___ (mo/dd/yy)
Age in years	Unk	___/___/___ (0 = <1 yr) Fetus
Sex	Unk	F—M
Race*	Unk	1—White—2—Black—3—WHisp—4—BHisp 5—AmerI—6—PacI—7—Asian—8—Other
Injury Date	Unk	___/___/___ (mo/dd/yy)
FIPS Scene	Unk	___/___/___
Scene City		
FIPS Home	Unk	___/___/___
Home City		
E-Code	Unk	E ___/___/___
E-Code 849	NA	E ___/___/___
Work Related	Unk	Y—N
Safety Equipment*	NA	1—None—2—Belt/Harness—3—Bag/Belt 4—Bag Only—5—Child Seat—6—Helmet 7—ProClothes—8—Other

~~* See Instruction Book for table detail~~

PART 2

Alcohol	NA	Unk	—./
Drugs*	NA	Unk	N Y Amph Barb Benz Coc Marij Opiate PCP
Glasgow Total	NA	Unk	—/
Systolic BP	NA	Unk	—/—/
Resp. Rate	NA	Unk	—/—/
Resp. Rate Status	NA	Unk	1 Vent 2 Intub. 3 Both
Disposition	NA		1 Home** 2 AMA 3 Obser 4 Floor 5 SDown 6 ICU 7 OR 8 Txf 9 Death
NCode 1			—/ /—.
NCode 2	NA		—/ /—.
NCode 3	NA		—/ /—.
NCode 4	NA		—/ /—.
NCode 5	NA		—/ /—.
Discharge Disp*			1 Home** 2 AMA 3 ACareF 4 InPtRehab 5 SkCare 6 ResFac 7 Expired
Facility Out***	NA	Unk	—/ /—/
Hospital Days***	NA		—/ /— (000—<1 day)
Expression***	NA	Unk	1DTH 2DPH 3ID 4I *
Feeding***	NA	Unk	1DTH 2DPH 3ID 4I *
Locomotion***	NA	Unk	1DTH 2DPH 3ID 4I *
Rehab Potential***	NA	Unk	1 Poor 2 Fair 3 Good
Billed Charges		Unk	\$ —/ / / / /
Primary Payment Source		Unk	A, B, C, D, E, F, G, H, I, J*

393

394 * See Instruction Book for table detail

395 ~~** Not applicable to Head and Spinal Cord Reporting~~
396 ~~*** For Violent Injury Reporting will only be included if the patient had an in-patient stay~~
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398 (Source: Repealed at 46 Ill. Reg. _____, effective _____)